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ORIGINAL ARTICLE

FAMILY STRENGTHENING INTERVENTIONS FOR MANAGING CHILDREN WITH SICKLE CELL ANEMIA[1]

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ABSTRACT

Objective: understanding the family coping for the management of the child with sickle cell anemia. **Method:** a qualitative study of a case study type conducted in a school clinic in the Central Western Region of Brazil. The unit of analysis was a single parent family consisting of the mother and the seven-year-old son. The reference of the Interactional Model of Family Care guided the intervention plan, consisting of eight meetings every two weeks for four months. **Results:** from the narratives were raised the hypotheses of suffering and proposed interventions that involved listening tries, clarifying doubts, offering information, encouragement and praise to the family forces. It appears that the family faces adversity based on its strength and interactions with health professionals, perceiving it more resilient and empowered with the interventions offered, which promoted its understanding of the disease and the perception of its safety for care. **Final thoughts:** Family empowerment enables better understanding of the disease by the members, leading them to feel safer for care, in an environment of welcome and appreciation. Interventions that strengthen family resilience have the potential to help the family manage children with sickle cell anemia.

Keywords: Family support. Sickle cell anemia. Child health. Family nurses.

INTRODUCTION

Sickle cell anemia comprises a group of hereditary hemolytic anemias characterized by structural changes in the beta-globin chain, leading to the production of an abnormal hemoglobin called Hemoglobin S (HbS)[1].

Clinical manifestations occur since childhood, with intense and widespread pain throughout the body and susceptibility to infections. It is a chronic and unpredictable condition that can cause frequent hospitalization. In many regions of the world, it is a disease stigmatized by the fact that it is hereditary, presents a risk of death and by the constant painful crises[2,3].

From the diagnosis of the disease, families change their daily lives and need to adapt to provide the care that the child's clinical condition requires. In this context, they feel insecure and afraid due to the unpredictability of the disease and the child's future[4].

The literature highlights studies related to the adaptation of the family and the child to sickle cell anemia, taking into account family adjustments, coping strategies, quality of life, self-efficacy, among others[4-7]. However, few studies have presented results of interventions with families and on family processes based on theoretical models[8,9].

The care of families of children with sickle cell anemia should be organized in order to help them recognize their strengths and potentialities for coping with the situation. Listening to the family and identifying their needs guide nurses to propose interventions that strengthen their capacity for child care and decision-making[10,11].

The Interactional Model of Family Care

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(IMFC) underlies the practice of nurses with the family in the context of chronicity, promoting their empowerment to deal with adversities throughout the trajectory of the child's chronic health condition. The focus is on the family as a care system, considering vulnerability, resilience and the interactions and meanings that the family attributes to the experience of illness[12]. The central objectives of IMFC are: (i) to create and enhance resources in families, so that they can deal more effectively with the experience of the child's condition and recover in a strengthened way, (ii) to stimulate families in their capacity to face crisis situations, and (iii) to stimulate family resilience and resilience[12]. Therefore, the program has an organized structure to direct interventions with families.

Considering the relevance of systematized care for the care and strengthening of families in the experience of the chronic condition, we question: How do families of children with chronic health condition, such as those with sickle cell anemia, face the situations they experience in their daily life in the management of the child; and how do they respond to the interventions offered to them?

Thus, the objective was to understand the family coping for the management of the child with sickle cell anemia.

METHOD

This is a qualitative study, a case study[13] conducted in an Integrated School Clinic (ISC) of a public university in the Midwest. The choice for the qualitative approach is due to the fact that it considers the subjective dimension, such as the meanings, beliefs, values and attitudes of people[14], enabling a better understanding of the object under study.

The case study, in turn, allows the understanding of complex social phenomena, seeking to preserve the characteristics of events in real life. Therefore, the research was conducted according to the following components: definition of the study question; delineation of the study propositions; establishment of the unit of analysis; realization of data linkage and selection of criteria for the interpretation of the findings[13].

In the unit of analysis, the "case" to be studied was defined, that is, the coping of a child's family with sickle cell anemia. The "case" can be an entity, a single individual, small groups, communities or even specific decisions, programs and events[13]. In this study, the unit of analysis was a family that faced the diagnosis and treatment of a child with sickle cell anemia.

The sources of evidence most commonly used in conducting a case study are: documentation, archival records, interviews, direct observations, participant observations, and physical artifacts[13]. In this study we used the records of family care, recorded in the form of own evolution of care in the clinic, and the completion interview recorded after authorization by the family.

The participating family was referred to the ISC by the outpatient hematology team of a public reference service in the treatment of sickle cell anemia. The visits at School Clinic occurred on average every 15 days for a period of four months. In total, eight meetings were held, with an average duration of 45 minutes. The same participants were the mother and child (both were present in all eight meetings) and two health professionals: a nurse and a teacher.

In each meeting, the strengths, challenges, chances of suffering and changes made by the family were identified. In the first, we sought to hear the narrative of the experience with the management of the sick child, family functioning, interactions with health professionals and social equipment, such as association of patients with sickle cell anemia, school and community center. At that moment, the Genogram and the Ecomap of the family were built[12] and the hypotheses of suffering were identified.

In the subsequent meeting, the hypotheses of suffering were validated and the proposed interventions were discussed. In the other meetings, the mother narrated the changes made in relation to the management of the disease, asked for clarification of doubts and reported her perception about the successes achieved in family interactions.

In the last meeting, the mother was asked to report the actions taken and the changes made to deal with adversity situations. One month after the end of the meetings, a semi-structured interview was conducted with the child's mother

at the School Clinic, which was previously scheduled and conducted by the main author. It lasted 40 minutes, was audio-recorded after authorization, guided by the following guiding question: Tell me how you have been dealing with the coping and management of the child's care from the end of the visits in the clinic?

All actions performed during the meetings were recorded in the family evolution records filed at the Clinic. These records were enriched with observation data on the behavior of the mother and child during the meetings and impressions of the two researchers, one of them being a master and the other a PhD with experience in the subject and training for the application of grounded interventions in IMFC.

For analysis, the interview was transcribed in its entirety and, after, the material was submitted to the analysis process and followed the narrative research method with an approach to the categories with emphasis on content[15]. To do so, initially, significant excerpts that were later grouped forming the categories were highlighted, composing them by described contents that indicated the theme representative of the family experience and the changes made.

The checklist for qualitative research, the Consolidated Criteria for Reporting Qualitative Research (COREQ), was used[16].

The development of the study obeyed all the ethical precepts contained in Resolution 510/2016 that dictates the guidelines and regulatory standards of Research Involving Human Beings in Human and Social Sciences, and was submitted and approved by the Ethics Committee on Research with Human Beings (ECR) of the signatory institution (opinion n. 1.350.429).

RESULTS

The family under study is made up of a mother and a 7-year-old son with sickle cell anemia who was experiencing conflictual intra-family interactions; lack of knowledge about the child's health condition; financial overload and lack of social support; difficulty in the clinical and educational management of the child; and insecurity in the provision of care with maternal overprotection.

In Table 1, the family reports that allowed the identification of problems and the definition of the hypotheses of suffering are presented.

Table 1. Hypotheses of suffering in families of children with Sickle Cell Anemia.

Family Narratives	Description	Hypotheses of suffering
"We didn't know, we couldn't understand what sickle cell anemia was". *"I wanted to be more oriented, because there are many things that I do not understand, I do not know how to deal with".* *"It gives us despair to see that child crying, crying, with that unbearable pain".* *"Who is not afraid of losing a child? It is to come to the hospital to hospitalize, and suddenly receive the news that came to death".* *"Every moment for us is a risk. I'm afraid to enter the hospital with my son and leave without him".* *"To this day I could not understand, I do not believe he has, but I know he has and I do not want to accept".*	• Lack of knowledge about sickle cell anemia. • I'munpreparedtodealwithsicklecell anemia. • Fear ofcrisisand death. • Uncertaintyaboutthe future. • Difficulty to accept the chronicity condition caused by sickle cell anemia.	Emotional and relational demands of the family in the interaction with the context of sickle cell anemia of the child
"No one to share with, it's all behind my back". *"It's hard because I do everything alone, I had to have more help, because there are days that I want to leave everything".* *"I stopped working to give full attention".* *"I don't go to parties so he doesn't see candy and soda, otherwise he'll want it".* *"My eldest daughter says that I only like the son, says that I only stay with him in the hospital".*	• Family overload. • Lack of support and social network support. • Disorganization of family life due to unexpected hospitalizations. • Overprotectionandinvisibilityofchildhood. • Difficulty in therelationship with other children.	Demands on the family's ability to function
"It's all a damned complication..." (about the difficulty in having access to medication and that sometimes goes missing). *"Lack a little more attention, information"* (about the nursing team when the child is hospitalized).	• Lack of dialogue with the team. Difficulty in accessing support structures and public policies.	Demands and crises in interaction with the team

Source: Adapted from Marcheti, M.A; Mandetta, M.A. Children and adolescents with disabilities: nursing intervention program with the family – Goiânia: AB, 2016.

The hypotheses identified were discussed with the mother of the child, who reflected on them and, from this, possible interventions were presented to promote the strengthening and acquisition of skill and confidence to continue with renewed forces. The way they would be put into practice and the type of participation desired were discussed with the consent of the mother, and were gradually implemented.

Table 2 shows the interventions implemented during the meetings.

Table 2. Interventions offered to the family of children with sickle cell anemia, according to the Cognitive, Affective and Behavioral Domains

Meeting	Interventions
1st meeting	**Cognitive domain:** Information and guidance on the warning signs of the disease and most common complications in this age group. **Affective domain:** The emotional responses of the family were validated with it. The mother manifested fear for the future of her son, anxiety, fear of the unknown. **Behavioral domain:** The mother was encouraged to share the child's care with the father and organize moments of rest and leisure for herself.
2nd meeting	**Cognitive domain:** Offered text for reading on the development aspects of the child with sickle cell anemia at school age. **Affective domain:** Encouraging the narrative of situations experienced and validated family anguish. **Behavioral domain:** Encouraged the mother to empower and prepare the child for self-care and for her to identify her own needs.
3rd meeting	**Cognitive domain:** Clarified family doubts about the evolution of sickle cell anemia. Affective domain: Instilling hope and optimism and encouraging persistence in efforts for change. **Behavioral domain:** Encouraged empathic and honest communication between mother and child.
4th meeting	**Cognitive domain:** Shared information about child care during the winter season to minimize sickling crises and the need for continuous use of chemoprophylaxis.
5th meeting	**Cognitive domain:** Provided information on disease transmission. Illustrations used to explain the genetic transmission of sickle cell anemia.
6th meeting	**Cognitive domain:** Shared information on the pathophysiology of sickle cell anemia and reinforcement of prophylactic care during the winter season. **Affective domain:** Hope and optimism encouraged, reinforcing the family's potential to overcome adversity. **Behavioral domain:** Encouraged the family to persist in their efforts for the necessary changes. Reinforced the need to develop in children their potential for self-care.
7th meeting	**Behavioral domain:** Deliver teaching material with simple and illustrative writing about sickle cell anemia to be shared with other family members and with the school the child attends. **Affective domain:** The narrative of situations experienced in the context of the disease and the sharing of thoughts and emotions are encouraged. **Behavioral domain:** Family encouraged to persist in their efforts and accept human limitations, and to develop empathetic communication strategies.
8th meeting	**Cognitive domain:** Praised the strengths and competencies of the family, with openness to the necessary changes in the management of the disease and family interactions. **Affective domain:**Strengthened and encouraged hope, optimism and the family's potential to overcome adversity.

The family narrated the changes that occurred in the way they dealt with the context. He revealed that he felt more competent to position himself in the situation, facing it safely, with more knowledge and recognition of his strength to manage the child's disease.

From the analysis of the interview, a category emerged, which is described below:

Family Empowerment

In this category, reports were included in which the mother expresses the way the family faces the management of the child with sickle cell anemia, from the interventions offered in the school clinic. It consists of three subcategories: a) *the understanding of the disease and its repercussions on child development*; b) *the feeling of security for care*; c) *reception and appreciation by professionals*; and d) *the stimulation of the child for self-care*.

The interventions provided the strengthening of the family unit, which was facilitated by the in-depth understanding of the disease, the establishment of a safe environment for care, the offer of emotional support and the autonomy of the child in self-care. In this way, the family felt safer for the care of the child, since it found a

space to openly dialogue about the concerns regarding the disease, such as physiological aspects, clinical manifestations and treatment.

a) Understanding the disease and its repercussions on child development

The family suffers from ignorance of the disease. When receiving the diagnosis, information does not always make sense for the family at the moment, and often is not understood by it. She seeks information, especially on the internet, is faced with content that brings uncertainty and that afflict her even more. The intervention "offer information and guidance on sickle cell anemia and the care of the child with the disease" enabled the family to clarify their doubts throughout the meetings. When receiving explanations in an open dialogue environment, through conversations, the delivery of informational materials, and the indication of trusted sites, the family felt free to ask questions and clarify their doubts.

> Here (in the program space) I felt more comfortable to ask questions, because I did not know what it was and did not know how to do.

> WhatsApp helps a lot as a means of communication, when I had doubts you could help me.

Family doubts were related to the cause of the disease, that is, the way its genetic transmission occurs; and on the effect of medication, the pathophysiology of the disease and child development. The mother had difficulty identifying, in the behavior of the child, what was proper to the stage of development in which she was, and what was a manifestation of the disease. By learning more about each stage of child development, the family began to differentiate what was a behavior due to the disease and what was proper to the phase in which the child was.

> I thought everything was from the disease, I could not identify what was proper to the age he is and what is a symptom of sickle cell anemia, the cause and how it was transmitted. Nobody explained about the medications and how to care at home.

> The texts and all the explanations that were given here helped me and helped my family to understand that the things he had was because he was a child and not because he had sickle cell anemia. I was able to identify that difference.

As the family appropriated the various aspects and information about the manifestation of the disease, felt safer to explain to the people of their living about the clinical condition of the child and the care he should receive, and realized more empowered and informed to the point of going to school to talk about the care and attention that the school should take with the child.

> I took the booklets you gave me to school and now they (the teachers) know what he has, talked to me, and told me they did not know that his anemia was so serious. It was very important for everyone who has contact with him at school, and reassured the family more.

> Now I can explain to someone else what he has, because before did not even know how to explain what he had.

Still regarding the understanding of the disease, the family pointed out that interventions would be even more useful if they occurred in the immediately post-diagnosis phase of the disease when they realize that they need more information to know how to deal with the situation. The family considers that the moment of discovery of the disease requires a space in which all family members can be informed and clarify the doubts. For her, this is a desperate time when everyone needs to express their fears. Being able to talk relieves suffering from a family perspective.

> As soon as I had it, I had no idea what sickle cell anemia was, so if I had that guidance early on, a lot would have been easier. If it was early on I would know how to deal more. The family was lost, without information, without knowing how to deal. Heartache for the fear of what would be.

b) The feeling of security for care.

As the family comes to understand the disease better, the most frequent fears about the care the child requires are being eased. The family feels safer to face and manage the disease, and deal with the context of its treatment. In this sense, it changes the family dynamics and spends organizing your time seeking greater quality, both for the mother, so

that she can devote a little more to personal care, as for the child, growth in a less restrictive and conflicting environment.

The family mobilizes to allow the child to participate in activities and games proper to his age and to favor his interaction with other children, failing to see him as sick and limited and seeing him as a child requiring special health care, but who remains a child.

> Today I cannot just take care of him, I sleep all night, do not wake up every hour. That fear of not being able to stay away from him for a minute is over. Before I thought he was like a penis and could not do anything because of his problem, today he plays ball, rides a bike [...].

> I started to have more confidence in how to deal with him, with his illness and nowadays I no longer see him as a poor child, he is a normal child.

c) Reception and appreciation by professional

The family feels welcomed as they realize that someone has certified the care offered to the child, validating, recording and valuing their efforts. This support of the team is perceived in the reading of the letters he received during the meetings in the clinic. Reading about the recognition of their efforts and mobilizations helps in coping and causes feelings of happiness and appreciation. He recognizes that having someone who listens to his anxieties, fears, and even conquests with the child and about what is happening in the family, is configured in a space of reception and appreciation of his efforts in caring for him.

> I was happy with the letters I received, because even today if someone thought I took good care of him, he said nothing to me, but it was written there in the letter that I take good care of him.

> Here I have someone to talk to, I have someone to tell what is happening to me and my son, because no one asked how I was, here was a space to vent, a safe haven.

Also, the family feels strengthened and valued and rescues forces that were unknown to him, becoming empowered as it manages to handle the situation. The opening of family spaces for conversations and interactions allowed the feeling of mutual belonging to emerge, with the rescue of dialogue, favoring decision-making.

> Improved our conversation at home, today I can talk more with him, today I sit down to talk and listen to him.

> Today I am more strengthened; I did not know that I had strength. I managed to rescue my strength. At home we are talking more.

> Before everyone was together, but disoriented, was each for himself and God for all, today we are able to walk together for real, today we can sit and talk. I think today we really are a family.

d) Stimulating the child for self-care.

Coping with family to manage child care involves understanding that the child's chronic health condition will require lifelong care. In this way, the family mobilizes to prepare the child for self-care, so that he can have autonomy to take medicines and have knowledge about his disease.

> Today he takes a few pills, alone, and if someone asks what he has, he says he has sickle cell anemia and explains exactly what it is.

Promoting family empowerment through interventions favored the strengthening and successful functioning of the family, helping it to continue feeling safer to care for the child and promote its healthy growth and development. By better understanding the disease and perceiving itself valued, the family moves towards facing the disease with more naturalness and mastery of the situation.

DISCUSSION

In this study, family empowerment is the way in which the family is able to face the management of sickle cell anemia, which consists of *understanding the disease and its repercussions on child development*; the *feeling of security for care*; and *care appreciation by professionals*; and the *stimulation of the child for self-care*.

For the family, it is difficult to deal with the uncertainties arising from the diagnosis, since it does not know its genetic heritage and only becomes aware of the child's health condition

after the neonatal screening test or as a result of the first crises in childhood[3,4,5]. This fact is a potential stressor for the family, since this chronic health condition will require constant adaptations in the roles and routine of family members in order to seek to meet their care needs[4,5,9].

The IMFC represents a space in which the family has the opportunity to be heard in its experience, and strengthened for the management of the disease and the care of the child, finding the support it needs to renew its forces in the itinerary with the child[10].

Being heard and having your doubts clarified is essential for the family to continue in its trajectory, with a new perspective on its capacity for care, changing the way it deals with the child.

Studies have corroborated this finding, showing that the offer of interventions focusing on attentive listening to the family's life experience, transformed by the child's illness, has the potential to promote the forces and change organizational patterns of family functioning[10,12,17,18]

In this case, the family expanded their knowledge about sickle cell anemia, through interventions in the cognitive domain; felt safe for child care, through interventions in the behavioral domain and felt more strengthened to make decisions, because she could reflect on her situation, and talk about the feelings and demands that overwhelmed her. The changes in family interaction were perceived by her, from the interventions proposed in the affective domain of the family.

The nurse, as well as the other health professionals is considered essential for the monitoring of the child with sickle cell anemia and the family, since they establish strategies for an active participation in self-care, therapeutic guidelines that stimulate the maintenance of treatment, as well as propose educational actions that can influence health promotion. Thus, the main goal should be to improve the quality of life of children, reducing acute and chronic complications provided to their physical, emotional and social environment[19].

The promotion of health literacy with the development of adequate and validated reading materials is essential to promote the empowerment of families. One example is the tracking and health guidance booklet on sickle cell disease developed by researchers in the northeastern region of Brazil. The authors suggest that this material is used by professionals as an important intervention tool[20].

Another change perceived by the family was the recognition of their confrontation in the trajectory of child care. This change was triggered by narrating her experience, and reliving the challenges faced leading her to recognize her resources and capabilities for managing the disease and coping with the current situation.

The nurse should promote projects and implement actions in health care scenarios, in order to ensure greater rapprochement with these families, strengthening and supporting the family nucleus for coping, thus avoiding worsening of crises and frequent hospitalizations[5].

The fear of crises or worsening of the disease produces overprotection and resignification of childhood by the family, previously considered normal for something fearful and uncertain. Overprotection refers to how family members perceive the weaknesses of the child's health. The child's symptoms can exaggerate the family's concern and overprotection, pointing to the difficulty in solving the situations that frighten the family.

The disease has a significant impact on the exercise of the activities of the child and adults, and the whole family. It leaves marks that extend from birth to the end of life, causing difficulties that are articulated to others and creating repercussions in the short, medium and long term[21].

The empowerment of the family through interventions, such as being encouraged, allows the family to continue in changes in the way of care, before overprotective, preventing the child from playing and having a life closer to the ordinary for his age, which generated suffering in both the child and the family. It is revealed here one of the ideas presented in the IMFC, that families feel encouraged as they perceive themselves encouraged in their potential, both individual and family, to face the context in which they operate[10].

Also, the empowerment is being obtained in the interventions *be advised* and *receive information* through sending therapeutic letters, discussion of texts and conversations during because the family has the opportunity to change the way it defines the situation and starts to establish new family interactions based on the reflections made, collaboratively among its members. Counseling, along with qualified listening, interactive dialogue and therapeutic communication are conditions for the effectiveness of care, and these occur when the nurse acquires knowledge and sensitivity that allows him to perceive the family, concerns arising from the condition experienced[4].

It is noticed that the family management is changing over time, according to the demands of care presented by the child, favoring the acquisition of skill for care, because each family will handle differently the situation faced.

It is recommended that professionals, regardless of family management style, it is essential to explore the points of view of family members and identify their difficulties, conflicts and potentialities in order to help propose interventions focusing on the empowerment of families and the acquisition of knowledge and skills to care for children[5].

The choice of a family for the case analysis may have limited the understanding of other dimensions of coping with the child's family with sickle cell anemia. Therefore, we suggest that, from the results pointed out in this study, there is the proposition of new studies with other methodological designs in order to enable advances related to the results obtained.

The Case Study enables in-depth understanding of the complexity of specific situations. Therefore, what is gained in richness of details, multidimensionality in the analysis and proximity to the research participants, is lost in general.

In this study, the family had faced the first years of the child's life without the necessary support to manage the clinical condition imposed by the disease. The narratives reveal that the systematic family intervention, at the beginning of the trajectory, of the diagnosis and treatment of the child, would have spared suffering to the family.

The Interactional Model of Family Care is an approach to lead the nurse in the process of caring for the family of the child with chronic health condition, as it is a space where the family perceives itself welcomed to talk about their experiences and concerns, clarify their doubts, expose their fears, express their feelings and emotions regarding the event of having a child with sickle cell anemia[12].

We recommend teaching this model in graduation to give subsidies for nurses to learn to include the family in care in a systematic way.

It is considered that this study is limited to the specific context researched; thus, the data should not be generalized.

FINAL THOUGHTS

We seek to understand how the family faces the management of the child with sickle cell anemia. From the analysis of the case, we understand that family empowerment is constituted as the way of coping with the family from their interactions in care at the Integrated School Clinic.

The family is empowered to face the management of the child when she comes to understand about the *disease and its repercussions on child development; to feel safe for care; to realize the reception and appreciation by professionals*; and *by stimulating the child to self-care*.

The interventions offered based on the Interactional Model of Family Care helped her access her own resources, contributing to the better management of the child and his clinical condition, as well as the family routine before the changes triggered by the disease, strengthening it for child care and decision making.

INTERVENÇÕES FORTALECEDORAS DA FAMÍLIA PARA O MANEJO DA CRIANÇA COM ANEMIA FALCIFORME

RESUMO

Objetivo: compreender o enfrentamento da família para o manejo da criança com anemia falciforme. **Método:** estudo de abordagem qualitativa, do tipo estudo de caso realizado em uma clínica escola na região centro oeste

do Brasil. A unidade de análise foi uma família monoparental constituída pela mãe e o filho de sete anos. O referencial do Modelo Interacional de Cuidado à Família norteou o plano de intervenção, constituída por oito encontros com periodicidade quinzenal, durante quatro meses. **Resultados:**a partir das narrativas foram levantadas as hipóteses de sofrimento e propostas intervenções que envolveram escuta tenta, esclarecimento de dúvidas, oferta de informações, encorajamento e elogio às forças da família.Depreende-se que a família enfrenta as adversidades com base em sua força e nas interações com os profissionais de saúde, percebendo-se mais resiliente e empoderada com as intervenções oferecidas,que promoveram seu fortalecimento, pautado na compreensão da doença e na percepção de sua segurança para o cuidado. **Considerações finais:** O empoderamento familiar possibilita melhor compreensão da doença pelos membros, levando-os a sentirem-se mais seguros para o cuidado, em um ambiente de acolhimento e valorização. Intervenções fortalecedoras da resiliência familiar tem potencial para ajudar a família no manejo da criança com anemia falciforme.

Palavras-chave: Apoio familiar. Anemia falciforme. Saúde da criança. Enfermeiras de família.

INTERVENCIONES FORTALECEDORAS DE LA FAMILIA PARA EL MANEJO DEL NIÑO CON ANEMIA FALCIFORME

RESUMEN

Objetivo: comprender el enfrentamiento de la familia para el manejo del niño con anemia falciforme. **Método**: estudio de abordaje cualitativo, del tipo estudio de caso realizado en una clínica escuela en la región centro oeste de Brasil. La unidad de análisis fue una familia monoparental constituida por la madre y el hijo de siete años. El referencial del Modelo Interaccional de Cuidado a la Familia orientó el plan de intervención, constituido por ocho encuentros con periodicidad quincenal, durante cuatro meses. **Resultados**: a partir de los relatos fueron planteadas las hipótesis de sufrimiento y fueron propuestas intervenciones que involucraron escucha activa, aclaración de dudas, oferta de informaciones, estímulo y elogio a las fuerzas de la familia. Se infiere que la familia enfrenta las adversidades con base en su fuerza y en las interacciones con los profesionales de salud, percibiéndose más resiliente y empoderada con las intervenciones ofrecidas, que promovieron su fortalecimiento, basado en la comprensión de la enfermedad y en la percepción de su seguridad para el cuidado. **Consideraciones finales**: el empoderamiento familiar posibilita una mejor comprensión de la enfermedad por los miembros, llevándolos a sentirse más seguros para el cuidado, en un ambiente de acogida y valorización. Las intervenciones que fortalecen la resiliencia familiar tienen el potencial de ayudar a la familia en el manejo del niño con anemia de células falciformes.

Palabras clave: Apoyo familiar; Anemia falciforme; Salud del niño; Enfermeras de familia.

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